DOCUMENT RESUME

ED 229 632 CE 036 007

AUTHOR Rice, B. Douglas; And Others
TITLE Independent Living Rehabilitation: Program Development, Management, and Evaluation.
INSTITUTION Arkansas Univ., Fayetteville. Arkansas Rehabilitation Research and Training Center.; Texas Inst. for Rehabilitation and Research, Houston.
SPONS AGENCY National Inst. of Handicapped Research (ED), Washington, DC.
PUB DATE Feb 83
GRANT G008003045
NOTE 71p.
AVAILABLE FROM Arkansas Rehabilitation Research and Training Center, Publications Department, P.O. Box 1358, Hot Springs, AR 71901 (Item #1202, $4.00).
PUB TYPE Guides - Non-Classroom Use (055)

EDRS PRICE MF01/PC03 Plus Postage.
DESCRIPTORS *Deinstitutionalization (of Disabled); Delivery Systems; Disabilities; Federal Legislation; Human Services; Mental Retardation; Models; Normalization (Handicapped); *Program Administration; *Program Development; *Program Evaluation; Rehabilitation Programs; Staff Development; Vocational Education; *Vocational Rehabilitation

ABSTRACT

This manual is designed for use by staff development personnel and other trainers in presenting an orientation to independent living programing for rehabilitation agencies and other human service organizations. The three chapters in unit 1 define independent living, identify the major historic events contributing to the development of independent living, and provide detailed information on significant legislation. Unit 2 addresses development and management of independent living programs. Its five chapters describe models for independent living programs; discuss generic services commonly found in independent living programs; consider staff positions, duties, and responsibilities; overview the role and function of the rehabilitation counselor in independent living settings; and identify evaluation criteria. The first chapter in the closing unit focuses on vocational rehabilitation and reviews the rationale for the independent living rehabilitation services to be provided by state vocational rehabilitation agencies. The final chapter of the manual highlights a number of important concerns in independent living. The issues are phrased in the form of questions to stimulate discussion leading to identification of alternative solutions or recommendations. (Each chapter concludes with a summary and notes to the trainer.) References and an appendix listing training resources are included. (YLB)

Independent Living Rehabilitation: Program Development, Management, and Evaluation

B. Douglas Rice
Richard T. Roessler
Reed Greenwood
Lex Frieden

Arkansas Rehabilitation Research and Training Center
and
The Institute for Rehabilitation and Research

February, 1983

Table of Contents

Foreword

Since it represents a significant departure from the traditional vocational rehabilitation delivery system, independent living creates a number of issues, concerns, and questions for vocational rehabilitation agencies as well as for evolving independent living programs. Therefore, this manual is designed for use by staff development personnel and other trainers in presenting an orientation to independent living programming for rehabilitation agencies and other human service organizations.

Combining shorter versions of other more lengthy publications produced by the authors with new material, the various sections of the manual are designed to be used flexibly by trainers. For example, some groups of trainees may need detailed information in only a few of the areas. For other groups, the trainer may wish to present the topics in a different sequence. This flexibility in presentation is necessary since independent living is a relatively new concept and since concerns may vary from one agency to another or from one situation to another. An edited version of this text has also been developed as a script for a tape/slide presentation on independent living available from The Institute for Rehabilitation and Research (Houston, Texas). Trainers may wish to use the tape/slide materials at some point in the orientation, e.g., initially to provide an introduction to independent living or at the end to review major topics.

This publication was made possible through the assistance of Barbara Wampler, who typed the manuscript, Julee Holmes, who typeset the text, and Janie Marks, who designed the cover and coordinated production.

The contents of this publication were developed under a research and training center grant (G008003045) from the National Institute of Handicapped Research, Office of Special Education and Rehabilitative Services, Department of Education, Washington, D.C. 20202. However, these contents do not necessarily represent the policy of that agency, and you should not assume endorsement by the Federal Government.

Unit I
Introduction to Independent Living (IL)

Chapter 1: **Defining Independent Living**

The Fifth Institute on Rehabilitation Issues (IRI). ***The Role of Vocational Rehabilitation in Independent Living*** (1978) and the Seventh IRI. ***Implementation of Independent Living Programs in Rehabilitation*** (1980). identified many controversial issues related to independent living. Major issues in independent living programs include:

1. Consumer vs. agency control of programs
2. Eligibility criteria
3. Priority for client selection
4. Duration of services
5. Types of services
6. Funding
7. Program evaluation
8. Accountability

As these issues and other concerns are resolved. the stated objective of independent living services. "individualized services with consideration to the person. community. disability. family and resources." will become a programmatic reality. In order for this to happen. agreements must evolve that are consistent with the intent of the IL legislation and the goals of IL consumers and their advocates.

Functional Description of Independent Living

Independent living has been given many definitions. For example, one comprehensive definition is as follows. Independent living—the ability of the severely disabled person to participate actively in society. to work. to own a home. to raise a family. to participate to the fullest extent possible in normal activities. and to exercise freedom of choice and personal control over one's life (Cole. Sperry. Board. & Frieden. 1979: Roberts. 1977. and Fifth IRI. 1978). The Independent Living Research Utilization Project at the Institute for Rehabilitation and Research (Frieden. Richards. Cole. and Bailey. 1979) described independent living as. "Control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities. This includes managing one's own affairs. participating in day-to-day life in the community. fulfilling a range of social roles. and making decisions that lead to self-determination and the minimization of psychological or physical dependence upon others. Independence is a relative concept that may be defined personally by each individual."

Generally speaking. independent living emphasizes *freedom of*

choice, personal control of one's life, and participation in significant roles of worker, homemaker, and provider

The Objectives of Independent Living

The concept of independence depends upon each individual's status at the time services are initiated. Independent living has as its basic premise that each person can learn to live more independently as reflected in these graduated objectives:

1. To live more independently, e.g.,
   a. through institutional care such as a nursing home
   b. in a rather large group living arrangement such as an independent living center
   c. within a small self-help group complex
   d. with family or friends in an apartment or home
   e. alone or with an attendant in an apartment or home
2. To work more effectively and independently, e.g.,
   a. in the home
   b. in a sheltered situation
   c. in competitive employment

Even within these situations, individual needs will differ in terms of attendant care, home modification, job modification, assistive devices, health maintenance, transportation, and other services essential for successful independent living.

Defining Independent Living Rehabilitation Services

There are two approaches to defining Independent Living Rehabilitation (ILR).

1. One can say what ILR **is**.
2. One can say what ILR **is not**.

As an example, ***ILR is not***:

1. Rejecting for services those with the greatest need.
2. Emphasizing totally the need for the individual to change in order to accommodate environmental demands.
3. Viewing independent living rehabilitation as somehow competing with the goals of vocational rehabilitation.

ILR is:

1. A program of services for severely disabled individuals who, through these services, can have more freedom of choice and control of their lives.
2. An advocacy resource promoting the rights of individuals with disabilities.

3. A program of services resulting in changes in the environment, e.g., housing, public buildings, transportation, and job modification.
4. A segment of a more comprehensive system along with vocational rehabilitation, referred to as rehabilitation. ILR and VR should be viewed as complimentary to each other rather than as competing with each other.

Vocational Rehabilitation agencies have promoted the basic principles of independent living, specifically for clients with vocational potential. Recent legislation, however, has added a ***new dimension*** *to the concept of independent living by extending these services to individuals not previously eligible as a result of severe disabilities and/or no present vocational potential.*

Defining Independent Living Rehabilitation Services

Independent Living Rehabilitation Services (ILR) are defined in the Fifth IRI (1978) as, "ILR refers to a formalized program of services designed to assist severely handicapped individuals adjust, function, and live as independently as possible within the community of their choice."

Turem and Nau (1976) noted, "A program of rehabilitation for independent living is one which would provide comprehensive services to improve the ability of severely handicapped people to live independently or function normally within their family or community without reference to a vocational goal."

Describing Independent Living Centers

Many independent living services will be provided at an independent living center as authorized under Title VII, Part B of PL 95-602 (1978). In reference to these centers, the proposed regulations state "These centers are expected to be multi-purpose facilities able to provide a broad range of assistance to severely handicapped persons in order to help them to achieve greater independence in either their family or community living situations" (Federal Register 11/28/79, 1362 100)

Summary

Although not a new concept, independent living represents a new program area in the rehabilitation legislation. Developed to reach individuals previously excluded from vocational rehabilitation, this

program is referred to as independent living rehabilitation. Independent living rehabilitation is designed to enhance severely disabled individuals' abilities to determine their own destinies, to participate in all areas of society, and to contribute to, as well as share responsibility in, community life. Independent living rehabilitation is not intended to compete with but to complement vocational rehabilitation and should be viewed as an integral phase of the overall "rehabilitation" process.

Notes to the Trainer

Important points to emphasize in presenting Chapter 1 include:

1. IL related topics requiring further clarification
2. Essential elements of the IL definition
3. The continuum of IL objectives
4. The nature of the IL/VR relationship

As a result of information in this section, participants should appreciate IL's vital role in the overall rehabilitation process.

Chapter 2: **The Development of Independent Living**

The independent living movement is comprised of a number of dedicated persons with disabilities and service providers who see the need to broaden rehabilitation's scope beyond its traditional vocational emphasis. It is an integral part of a broader civil rights thrust for all persons with special needs. As reported by Roberts (1977), the movement's strength comes from the fact that "it represents all people with special needs—the aged, the physically disabled, the developmentally disabled, and the mentally ill. At no time was this more apparent than during the Section 504 demonstrations in April, 1977. At that time, people of all different disabilities joined hands and demanded their full human and civil rights as equal Americans. This demonstration capped a series of efforts by the general public and legislators to achieve laws and guidelines that would open the doors to education, employment, housing, transportation, and recreation for people with special needs."

Therefore, independent living rehabilitation programs cannot be separated from the larger movement for equality of opportunity for handicapped Americans.

Independent living also has its roots in the consumer action and deinstitutionalization currents in American society. These forces stress the importance of life in the least restrictive environment, a goal attainable through comprehensive community based independent living programs. Roberts (1977) described the proper role for these programs. "Independent living programs deal with the quality of life people lead in the communities, they are service and training centers, but primarily they are advocates working to develop a public awareness of the needs and capabilities of people with severe disabilities, as well as an awareness within the disabled individual of his potential for a life of greater participation and involvement."

Because of the efforts of independent living programs in Berkeley, Houston, and Boston, the demonstrations such as those in 1977, and the impact of civil rights, consumerism, and deinstitutionalization forces in Congress and the legal system, federal legislation evolved that provided for independent living services and centers. This legislation initially funded these programs with the anticipation that they would move to other sources of support in the future.

An ever increasing number of independent living programs are being established throughout the country. These programs have grown in number as a result of the 1978 Amendments to the Rehabilitation Act of

1973. The mission of these programs varies according to clientele served, funding, staff, support services and organizations, resources, geographical areas, and services.

The major commonality among programs is:
*Each program provides services **without** a vocational goal test if these services will enable the person to function more independently in multiple social roles.*

Historical Overview

The Congress of the United States made attempts at various times prior to 1978 to provide independent living services to people with severe disabilities with no immediate potential to begin or re-enter employment. These initial efforts occured in 1959, 1961, 1965, and 1973. Rather than mandate the provision of IL services, the Rehabilitation Act of 1973 mandated a ***Comprehensive Needs Study*** (CNS) (Turem and Nau, 1976) "... to investigate, seek out, and determine the kinds, sources, approaches, and availability of existing and new services which could assist severely handicapped individuals to increase their capacities for independent living or more normal functioning in the community through the attainment of non vocational rehabilitation services ..." (RSA Background Paper on Independent Living, 1977).

Principal conclusions from the Comprehensive Needs Study were.

1. *An independent living rehabilitation program was a crucial need of many individuals with disabilities.*
2. *Individuals in the survey expressed needs for vocational, transportation, and medical services.*
3. *The major concern of many seemed to be accessibility. Barriers inside the home, in public transportation, and in public facilities presented major handicapping problems.*

As a result of the CNS study, and on the basis of the authority of Section 130 in the 1973 Act, RSA funded six independent living demonstration projects located in Seattle, Washington, New York City, New York, Peoria, Illinois (subsequently discontinued), Salt Lake City, Utah, San Antonio, Texas, and Berkeley, California. The Seattle and New York City projects were concerned with physical restoration services. Salt Lake City and San Antonio emphasized the role of state agencies in ILR, and Berkeley promoted a consumer based, consumer operated ILR program.

A study of these projects by the Urban Institute (Muzzio, LaRocca, Koshel, Durman, Chapman & Gutowski, undated) concluded

1. Severely disabled persons can benefit from independent living rehabilitation services.
2. ILR project clients had diverse needs that changed over time. Counselors must develop highly specialized individualized written programs, periodically re evaluate clients, and revise these programs accordingly.
3. Transportation and architectural barriers remain a major problem, and most service delivery programs have little direct control over these environmental barriers.
4. There is a need for developing ILR eligibility criteria to distinguish between those persons who need and can benefit from ILR and VR services.
5. There is a need for reporting and accountability criteria specifically for ILR—including special criteria for clients who need to be in an ILR program indefinitely.
6. Although most costs can be covered by similar benefits, the costs remaining to the ILR program will likely remain higher than VR costs. It will be essential to maintain updated information on similar benefits and coordinate programs and services to use them as much as possible.
7. High ILR costs are partly a function of the length of time in the program, many ILR clients were still not closed after 3 years.
8. Further exploration of alternative service delivery methods in ILR is needed. There are many possible ways of serving the ILR population, and proof is lacking regarding the effectiveness of the approaches (Rehabilitation Brief, 1979).

Trends

During the 1970's the independent living movement gained substantial momentum. Approximately 270 independent living programs in various forms are operating at present in the United States (TIRR, 1982). This trend is sure to continue when it is realized that nearly seven million Americans were identified in a recent national study as unable to carry out their major activity due to disability (DeJong, 1979).

Significant developments in the growth of the independent living movement are the:

1. Completion of the Comprehensive Needs Study mandated by the Rehabilitation Act of 1973.
2. Promulgation of the regulations in Sections 503 and 504 of the Rehabilitation Act of 1973.

3. Establishment of the American Coalition of Citizens with Disabilities as an advocate for equal rights for disabled persons.
4. White House Conference on Handicapped Individuals.
5. Campaigns to remove architectural, transportation, and attitudinal barriers.
6. Use of Federal Innovation and Expansion grants and Research and Demonstration funds to support the early development of independent living program models.
7. Use of state funds, as in California and New York, to support programs in independent living.
8. Passage of the Comprehensive Services for Independent Living Amendments (1978) to the Rehabilitation Act of 1973.
9. Implementation of ILR services through Part B of Title VII - PL 95 602 (Grants to state agencies to establish Independent Living Centers).
10. Two national conferences on independent living in Berkeley (1975) and Houston (1978).
11. Publication of seminal papers on independent living (De Jong, 1979. Nosek, Dart, & Dart, 1981. Nosek, Narita, Dart, & Dart, 1982. Stoddard, 1980).
12. Use of Title XIX and Title XX funds for attendant care.
13. Establishment of a Research and Training Center on independent living at the University of Kansas.
14. Establishment within the Council of State Administrators in Vocational Rehabilitation of a subcommittee on independent living.
15. Implementation of independent living services within state rehabilitation agencies.
16. Employment of individuals at the top management level in many state rehabilitation agencies with the sole responsibility of independent living services.
17. Creation of the Office of Independent Living for the Disabled (OILD) within the Department of Housing and Urban Development (HUD).
18. Establishment of independent living courses in university/college based Rehabilitation Education programs.
19. Allocation of national and regional short term training funds for training programs in various areas of independent living rehabilitation.
20. Selection of independent living services as a study topic for the Institute on Rehabilitation Issues in 1978 and 1980.

Summary

Continuing initiatives to launch independent living culminated in a Comprehensive Needs Study in 1973 and final legislative authorization for the program in 1978. Results of the Comprehensive Needs Study highlighted important areas of need, e.g., vocational, medical, transportation, and accessibility services. Several research and demonstration projects were concurrently implemented providing important information regarding IL programming.

With legislative authorization, independent living rehabilitation programs grew throughout the late 1970's. The expansion was principally the result of partial funding of Part B of Title VII of the 1978 Amendments. Many other programs and social initiatives supportive of independent living manifested themselves as a result of the need to serve some seven million individuals with severe disabilities.

Notes to the Trainer

Chapter 2 identifies the major historic events contributing to the development of independent living, e.g.,

1. The Comprehensive Needs Study
2. The five independent living demonstration projects
3. Inclusion of Title VII, Comprehensive Services for Independent Living, in the 1978 Amendments to the Rehabilitation Act.

Trainees should appreciate the significance of these events as well as of trends relevant to the development of independent living programs

Chapter 3: **Independent Living Legislation**

The Rehabilitation Act of 1973 as amended in 1974 and 1978 gave priority to services in a descending order of selection to the *most* severely handicapped, the *more* severely handicapped, and the severely handicapped.

Individuals in need of independent living services meet the requirements for the first priority group, the most severely handicapped.

The Rehabilitation Act of 1973 (PL 93-112):

1. Established priority for services to severely handicapped persons.
2. Provided for the Comprehensive Needs Study of severely handicapped individuals.
3. Established a national policy on services to severely handicapped individuals.
4. Established in Title V a civil rights provision for severely handicapped persons.
   a. ***Section 501*** provides for Affirmative Action programs for employment, placement, and advancement of individuals with disabilities within the federal government.
   b. ***Section 502*** creates the Architectural and Transportation Barrier Compliance Board.
   c. ***Section 503*** requires Affirmative Action programs for employment, placement and advancement of severely handicapped individuals by contractors receiving federal contributions in excess of $2500.
   d. ***Section 504*** requires nondiscrimination on the basis of handicap for programs and activities receiving or benefiting from federal financial assistance.

The 1974 Amendments

These Amendments redefined handicap to include functional limitations in one or more major life activities. This definition, which did not emphasize vocational potential, broadened eligibility and increased the impetus for independent living.

The 1978 Amendments

The Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments (PL 95-602) greatly expanded the range of rehabilitation services. In these Amendments, Titles III and VII are particularly significant for independent living.

Title III. Section 305 provides for grants to state rehabilitation agencies to establish and operate comprehensive community based rehabilitation centers (CRCs) These centers are designed to provide a broad range of services, information, and technical assistance to handicapped persons of the community and to local governmental units and nonprofit organizations.

Title VII (Comprehensive Services for Independent Living). After some twenty years of effort, independent living services became a legislative reality under 95-602. Funds, however, to carry out the provisions of these amendments are limited to Part B establishment of independent living centers. If Parts A and B are adequately funded in the future, comprehensive independent living services could be delivered to a large number of severely disabled individuals. A brief explanation of Parts A, B, and C of Title VII follows.

Comprehensive Services for Severely Disabled Individuals—Part A. Provisions are made for comprehensive services to any disability group including the older blind whose ability to engage or continue in employment or whose ability to function independently in family or community is severely limited. *Comprehensive Services* are defined as:

---

any service that will enhance the ability of handicapped persons to function better in employment or live more independently in the home or community.

The state rehabilitation agency is responsible for establishing comprehensive services.

Specific services are counseling (psychological, psychotherapeutic, and related services), housing incidental to the purpose of this section (including appropriate accommodations to and modifications of any space to serve handicapped individuals), appropriate job placement services, transportation, attendant care, physical rehabilitation, therapeutic treatment, needed prostheses and other appliances and devices, health maintenance, recreational activities, services for children of preschool age (including physical therapy, development of language and communication skills, and child development services), and appropriate preventive services to decrease the needs of individuals assisted under the program for similar services in the future (Part A).

Establishment and Operation of Independent Living Centers—Part B. Part B of Title VII provides for a grant program which authorizes the Commissioner of Rehabilitation Services to make grants to state rehabilitation agencies for "the establishment and operation of in-

dependent living centers, which shall be facilities that offer a broad range of services. These services include attendant care, independent living skills training, peer counseling, and assistance with housing and transportation. These centers are to make maximum use of other resources which are available to handicapped idividuals, e.g., Medicaid, Social Services, and housing assistance. A substantial number of these centers which will provide new opportunities for individuals with severe disabilities to live more independently in the community in the housing situation of their choice have already been funded on a three year grant basis (approximately $200,000 a year) by the Rehabilitation Services Administration. Programs funded by RSA are expected to secure their own funding when their grant expires.

Independent Living Services for Older Blind Individuals—Part C. Part C authorizes program funds from which the Commissioner of Rehabilitation Services may award grants to state vocational rehabilitation agencies to provide independent living services to older blind individuals. Services listed are specific to blindness, and include optical aids, braille services, and reader services. Programs eligible for funding under Part C would also be eligible for funding under Part B.

Summary

The Rehabilitation Act of 1973:

1. Established a service priority for severely handicapped persons.
2. Provided for the Comprehensive Needs Study (CNS) of severely handicapped persons:
3. Established a national policy for serving severely handicapped individuals; and
4. Established in Title V a civil rights title for severely handicapped persons through Section **501** (affirmative action in federal government, **502** (Architectural and Transportation Barrier Compliance Board), **503** (affirmative action by contractors of the federal government) and **504** (nondiscrimination on the basis of handicapping conditions).

The 1974 Amendments:

1. Defined "handicap" as including functional limitations and gave impetus to the independent living movement.

The 1978 Amendments contained three significant parts in Title VII.

1. Part A provided for independent living services without appropriations.
2. Part B authorized the establishment and operation of independent living centers and provided some initial funding.

3 Part C provided for independent living services for older blind individuals without appropriations.

Notes to the Trainer

Information in Chapter 3 provides more detail on significant legislation for independent living. This material may be presented in depth for some groups. For other groups, it may be appropriate to use the legislative detail in Chapter 3 on a selective basis, i.e., as a supplement to information presented in the previous section.

Unit II
Development and Management of Independent Living Programs

Chapter 4: **Independent Living Models**

The Seventh Institute on Rehabilitation Issues (Frieden, et al., 1979; IRI, 1980) describes three major types of Independent Living Programs

1. **Nonresidential**
   A Nonresidential Independent Living Program may be defined as: *a community based nonprofit program which is controlled by the disabled consumers it serves. The program provides services directly or coordinates services indirectly through referrals. Services are selected to assist severely handicapped individuals increase their self-determination and to minimize unnecessary dependence upon others.*

2. **Residential**
   A Residential Independent Living Program is, *a live-in program that provides directly, or coordinates through referral, shared attendant services, transportation, and other related services.*

3. **Transitional**
   A Transitional Independent Living Program is designed: *to facilitate the movement of severely handicapped people from comparatively dependent living situations to comparatively independent living situations. The primary service provided by these programs is skill training in such areas as attendant management, financial management, consumer affairs, mobility, educational/vocational opportunities, medical needs, living arrangements, social skills, time management, functional skills, sexuality, and others as identified. Transitional programs are usually goal oriented and/or time linked.*

There are other dimensions that can be used to identify types or models of independent living programs. Some of these dimensions are listed below.

Service setting - relates to whether a program is transitional, residential, or nonresidential.

Service delivery method - pertains to whether services are provided directly by the program or indirectly through referral to other agencies.

Helping style - the extent to which consumers are involved in operation of the program.

Vocational emphasis - whether or not vocational objectives are a component of the program.

Goal orientation - an ongoing or transitional program.

Disability type served - services to a specific disability type or to persons with a variety of disabilities.

Program sponsor. - supported primarily by health service, social service, rehabilitation service or an independent entity.

Management structure - the amount of control and/or influence exerted by the board of directors, executive director, or program staff.

Geographical type - serves primarily an urban or rural area.

Primary funding source - whether the program is supported primarily by fees for services, donations, rehabilitation agencies, other organizations, or grants.

Programs will differ along these many dimensions. In essence, the only rule of thumb for selecting an independent living model is to determine the needs of the target population of disabled persons and the availability of funds and then to design the most optimal program given local needs and constraints.

Examples of Existing Independent Living Programs

Some independent living program models are presented at this point to illustrate a nonresidential center, a residential center, and a VR-agency supported transitional ILR program. Selection of these programs does not represent an endorsement of them over other centers. Indeed, many other programs which are just as successful could have been described.

Nonresidential

Center for Independent Living (CIL), Berkeley, California

The CIL has no residential facilities and operates with a goal of total integration of severely handicapped individuals into community life. As Clowers, Haley, Unti and Feiss (1979) noted, the Berkeley program provides a full array of basic and specialized services, e.g., attendant referral, transportation, development of daily living skills, housing referral, financial and legal advocacy, wheelchair repair, and vocational training (p 101 102) Receiving special funding from RSA, the Veterans Administration, and other organizations to conduct special programs or projects, the CIL serves a large number of severely handicapped persons representing a wide range of disabilities each year.

Residential

Boston Center for Independent Living (BCIL) Boston, Massachusetts

BCIL's emphasis is on the severely handicapped individual's movement from relative dependence to independence. The program has three distinct phases.

1 Transitional Living - residents of an apartment complex receive training in social and daily living skills combined with attendant care as needed.

2. Cluster Housing modified apartments with an attendant pool and night attendants providing for more independence than transitional living.
3. Accessible Apartments independent living with residents in accessible apartments, usually shared with an attendant.

BCIL also provides nonresidential services to those people who choose to live in their own housing.

State Agency Supported

Texas Commission for the Blind, San Antonio, Texas

Using basic grant funds, the Texas Commission for the Blind provides a continuum of services designed to enhance the individual's independence. Through the use of "Extended Evaluation," visually impaired clients not only have the opportunity to develop vocational skills but also receive services that will assist them in living independently. Various subsidy programs are utilized to move clients through a series of housing arrangements, i.e., transitional living facilities, apartment unit complexes with support staff assistance, and independent living arrangements in one's home or apartment (Fifth IRI, 1978).

Summary

Major models for independent living programs include nonresidential, residential, and transitional. The model selected for a given community depends entirely upon the needs of the severely disabled individuals in that community and, to the degree necessary, the finances and resources available locally. In addition to differing in terms of models, programs will also vary along such dimensions as service delivery methods, vocational emphases, disability groups served, organizational structure, and funding sources. A well-known program representative of the non residential approach is the Center for Independent Living (Berkeley, California). The Boston Center for Independent Living is a comprehensive program including elements of all three models.

Notes to the Trainer

At the completion of this section, participants should understand the similarities and differences among independent living models. The rationale for selecting any one of these models emanates from the needs of individuals with disabilities in a given community.

Chapter 5: **Independent Living Program Services**

Many different schemes can be used to categorize independent living services. One can view services needed in terms of legislative mandates, particular program philosophies, or the day-to-day demands experienced by consumers. Differences in these perspectives can result in entirely different service patterns even though each of the programs would be referred to as an independent living program.

The purpose of this section is to describe "generic" services commonly found in independent living programs. The definitions used by the Independent Living Research Utilization (ILRU) project (Texas Institute for Rehabilitation and Research, 1981) serve as guides, and the emphasis in the section is on the types of services found in the combination IL skills development/community action program.

Legislation

The 1978 Amendments to the Rehabilitation Act of 1973 list numerous services that can be provided by independent living programs.

1. Intake counseling to determine the severely handicapped individual's needs and desires for specific independent living services.
2. Referral and counseling services with respect to attendant care.
3. Counseling and advocacy services with respect to legal and economic rights and benefits;
4. Attendant care and the training of personnel to provide such care.
5. Peer counseling;
6. Independent living skills, counseling and training, including training in the maintenance of necessary equipment, training in job-seeking skills, counseling on therapy needs and programs, and special independent living skills training for blind individuals or deaf individuals;
7. Housing and transportation referral and assistance;
8. Surveys, directories, and other activities to identify appropriate housing and accessible transportation and other support services.
9. Health maintenance programs;
10. Community group living arrangements;
11. Individual and group social and recreational activities;
12. Other programs and services designed to provide resources, training, counseling, services, or other assistance of substantial benefit in promoting independence, productivity and quality of life of severely handicapped individuals; and
13. Such other services as may be necessary and consistent with the

23

provisions of this title.

Of these services, the following are designated as core services which should be provided as a minimum:

- Information and referral,
- Attendant care,
- Housing referral,
- Peer counseling, and
- Financial benefits counseling.

Additionally, the definition of IL services under Public Law 95-602, the Comprehensive Services for Independent Living, is:

---

any appropriate Vocational Rehabilitation service (as defined under Title I of the Act) and ***any other service that will enhance the ability of a handicapped individual to live independently and function within his/her family and community,*** *and, if appropriate, secure and maintain appropriate employment. Such service may include any of the following: counseling services, including psychological, psychotherapeutic, and related services, housing incidental to the purpose of this section (including appropriate accommodations to and modifications of any space to serve handicapped individuals), appropriate job placement services; transportation, attendant care; physical rehabilitation, therapeutic treatment, needed prostheses and other appliances and services, health maintenance; recreational activities, services for children of pre-school age including physical therapy, development of language and communication skills, and child developoment services, and appropriate preventative services to decrease the needs of individuals assisted under the program for similar services in the future.*

The intent of the legislation is clearly to support a wide spectrum of services to assist the individual to become independent. In fact, the legislation appears to allow almost any service. Operationally, in any given community, independent living services should be selected because they meet needs unmet by existing programs and provide a catalyst for community awareness, social and political action, and independent living skill development.

Program Types and Component Services

One way to gain some understanding of the breadth of the services available from existing independent living programs is to review the services listed in the Registry of Independent Living Programs maintained by the ILRU project (Texas Institute for Rehabilitation and Research, 1981). A review of this registry revealed that four types of

24

independent living programs are included:

Independent Living Center (ILC) A community based, non-profit, non residential program which is controlled by the disabled consumers it serves. It provides directly or coordinates indirectly, through referral, those services which assist severely disabled individuals to increase personal self determination and to minimize unnecessary dependence upon others. The minimum set of services that are provided by an independent living center are housing assistance, attendant care, readers and/or interpreters, peer counseling, financial and legal advocacy, and community awareness and barrier removal programs.

Independent Living Transitional Program (ILTP) - An independent living program that facilitates the movement of severely disabled people from comparatively dependent living situations to comparatively independent living situations. The primary service provided by these programs is skill training in such areas as attendant management, financial management, consumer affairs, mobility, educational-vocational opportunities, medical needs, living arrangements, social skills, time management, functional skills, sexuality, and so forth. Additional services may be provided. Services of transitional programs are usually goal oriented and/or time-linked. As in any independent living program, a transitional program is community-based and offers opportunities for substantial consumer involvement.

Independent Living Residential Program (ILRP) - A live-in independent living program that provides directly or coordinates through referral shared attendant services and transportation. Related services which increase personal self determination and minimize unnecessary dependence on others may be provided. Like any independent living program, a residential program is community based and offers opportunities for substantial consumer involvement.

Independent Living Service Provider (ILSP) - An organization which provides several discrete services which can be used to increase an individual's ability or opportunities to live independently. For example, a medical rehabilitation facility may provide out-patient services which are designed to maintain the physical health of a person who lives independently in the community. However, if the center does not provide or coordinate a full set of services including transportation, attendant care and so forth, it would be an independent living service provider rather than an independent living program. While an independent living service provider does not meet the criteria necessary to be classified as an independent living program, the services it provides may be used or coordinated by an independent living program.

The Summer, 1981, listing (Texas Institute for Rehabilitation and

Research, 1981) contains 139 programs, of which 52 are independent living centers, 79 are independent living service provider programs, 7 are independent living transitional programs, and 1 is an independent living residential program. A summary of the services provided by these programs is presented in Table 1 (the latter two categories, ILRP and ILSP, are not included because of the small size of the groups). A review of Table 1 reveals that a wide variety of services are provided including some not usually included in the independent living category. This is explained by the group of programs under the ILSP category which are not technically considered independent living programs but programs which provide services which enhance independent living.

Because they have evolved, in many cases, from consumer efforts and, therefore, closely reflect the independent living philosophy, ILC service programs will be emphasized in this review. As can be observed from Table 1, these programs are mainly providing the first eight categories of services—

Information and Referral, Advocacy, Skills Development, Counseling, Community Awareness and Needs Assessment, Communications, Transportation, Social and Recreational.

Outside of the realm of employment and medical care, these services clearly reflect the philosophical basis of independent living. The next section provides a review of these eight major services and a brief discussion of the four remaining types of services.

Information and Referral. In addition to making referrals, independent living programs provide a focal point for information exchange about community services. Also, program staff are required to determine the needs of the newly referred disabled person and to assist the person in obtaining the services available through the program or in the community. Also, other types of information systems are available such as lists of potential attendants, accessible homes and/or apartments, or other needed resources which make independent living possible. In addition to developing and maintaining a resource library, IL programs must also be staffed by informed specialists who understand the procedural steps required to gain access to community services. The ILRU Registry also provides for three categories of information systems—information exchange, apartment registries, and attendant registries. Microfiche, accessible files, and computer retrieval systems are all possible resources for such systems.

Advocacy. Advocacy has many meanings. However, in the context of independent living, advocacy usually means acting on behalf of a

26

disabled person(s) to secure legal rights, public program benefits, barrier removal, and political and social action.

Advocacy is the core service for independent living.

In the case of persons who are not fully competent to handle their own affairs, advocacy may include protective supervision. Also, legal advocacy is conducted through public interest law centers, attorneys, and ombudsmen. Advocacy may take the form of an individual who acts as a citizen advocate on a one-to-one basis with an individual, a case manager advocate who is trained to represent the needs and rights of handicapped persons, or a systems advocate such as an organized group working to effect change on a broader basis through legislation and litigation.

Since they may assume a number of tasks varying from advocating for services, benefits, rights, understanding, legislation, funding, and acceptance, advocates must be knowledgeable regarding multiple programs and processes. Another point of concern is the ethical requirement in advocacy. For example, the advocate does not want to overprotect the individual and decrease the likelihood that the person will manage on his/her own initiative. If the advocate is a program employee, there may also be a conflict of interest since the employee is a potential adversary of the handicapped person should the person appeal decisions and/or services provided by the program.

Counseling. Counseling services take on a variety of forms in independent living programs including those listed in the ILRU Registry (peer, family, financial, vocational/educational, and para-legal). These counseling services in independent living are somewhat different from the usual professional counseling approach, particularly that influenced by the medical model with its heavy emphasis on intrapsychic problems. The counseling practiced in independent living centers stresses that many of the barriers to independent living are external to the person and that counseling involves much more emphasis on these environmental factors.

Since the term counseling is used to cover a broad range of interpersonal activities (even among professionals, no uniform definition is accepted), there may also be considerable diversity among counseling services in independent living programs. At a minimum, counseling services involve a combination of needs assessment and information/advice about services. The extent to which counseling exceeds these activities is open to question. However, implicit in the assessment and information giving functions is a knowledge of assessment procedures

Table 1
Independent Living Services on ILRU Register

	N equals 139 Total		N equals 139 Primary*		N equals 52 ILC		N equals 79 ILSP	
	%[1]	Rnk.[2]	%	Rnk.	%	Rnk.	%	Rnk.
Information and Referral								
Information Exchange Registry	61	8	35	6	92	4	39	13
Apartment Registry	58	10	31	9	98	2	37	14
Attendant Registry	51	12	37	4	96	3	19	21
Advocacy								
Advocacy (unspecified)	82	2	57	2	100	1	71	3
Political Lobbying & Organizing	47	13	13	20	69	10	33	16
Protective Supervision	18	21	6	25	2	22	30	17
Skills Development								
Independent Living Skills Training	83	1	64	1	88	5	77	1
Vocational Training	35	17	17	17	35	16	34	15
Mobility Training	51	12	30	10	52	13	52	9
Counseling								
Peer Counseling	74	3	53	3	100	1	54	8
Financial Aid or Counseling	69	7	36	5	92	4	54	8
Family Counseling	61	8	19	15	67	11	57	6
Vocational Educational Counseling	57	11	25	13	62	12	52	9
Para Legal	29	19	14	19	52	13	16	23
Community Awareness & Needs Assessment								
Community Consulting and Advising	70	6	32	8	87	6	58	5
Research	30	18	11	21	40	15	27	18

Communications								
Communications (unspecified)	60	9	24	14	77	8	47	11
Transportation								
Direct Transporation	72	4	27	12	83	7	66	4
Vehicle Modification	15	22	4	26	21	18	10	24
Social and Recreational								
Social and Recreational (unspecified)	71	5	34	7	71	9	72	2
Personal Care								
Attendant Services	45	14	32	8	48	14	43	12
Food Preparation	40	15	19	15	25	17	51	10
Housekeeping	37	16	18	16	25	17	47	1
Wheelchair Equipment or Repair	27	20	10	22	35	16	24	19
Residential	35	17	29	11	0	23	56	7
Employment								
Vocational Placement	40	15	16	18	48	14	37	14
Sheltered Workshop	14	23	9	23	8	21	19	21
Financial Support								
Financial Support (unspecified)	15	22	10	22	10	20	18	22
Medical Care								
Medical Treatment	18	21	8	24	13	19	22	20
Outpatient Services	14	23	10	22	8	21	16	23

*Those programs indicating this to be a primary service.

1 Percent of programs providing this service. 2 Rank order (1/most frequently provided service).

coupled with information about disability and its consequences, barriers and their removal, financial benefits and financial management, family services, vocational, educational programs, and para legal information and services. Also, another concern frequently expressed among disabled persons is the need for counseling regarding sexuality which has educational, human values, and emotional dimensions.

Independent living programs also have a unique opportunity to incorporate peer counseling in their services. The emphasis in peer counseling is on the use of peers as role models who can provide a receptive and understanding interpersonal relationship for another disabled person. The use of peers and paraprofessionals in counseling on many topics (from financial matters to sexuality) calls for training in such areas as interviewing, interpersonal communication, and information giving. Peer counselors represent an extremely valuable helping resource since they share a common bond in the disability area with those seeking independent living services. Peers possess firsthand experience to share and reflect on with another disabled person.

Preparation for peer counseling can be obtained through formal study, in service training programs, and individual study. It is important that independent living programs establish the boundaries for peer counseling services and provide peer counselors with the information needed to function effectively within those boundaries. Finally, counseling services should be provided through staff who have appropriate interpersonal, information giving, needs assessment, and goal setting skills. It should not be assumed that experience with disability is a sufficient condition for effective peer counseling. Additional information on the counseling service is provided in the section of this publication on the independent living counselor.

Skills Development. Independent living programs are concerned with the development of skills to enhance independent living. Through a variety of techniques (formal instruction, experiential activities, rap sessions, group activities), skills in a number of areas may be developed. As an example, the program offered in community living skills by the New Options Transitional Living Project (Cole, Sperry, Board, & Frieden, 1979) provides modules which are adaptable to many independent living programs. The modules cover attendant management, consumer affairs, financial management, functional skills, living arrangements, medical needs, mobility, sexuality, social skills, time management, and vocational/educational opportunities. The modules are designed to be used with a group leader, and information is provided on the program format and supplemental instructional resources. For example, the module on attendant management concerns three major topics—

alternative attendant arrangements, interviewing a potential attendant, and the attendant's perspective.

Such methods as those developed through New Options can be adapted on an individualized basis for use in any independent living program. Although it may be helpful to use trained instructors, it may also be possible to use experienced and knowledgeable disabled persons as group leaders.

Community Awareness and Needs Assessment. Community awareness is brought about through a variety of means and involves some of the components of advocacy. Assessment of the needs of disabled persons in a community can be done by a systematic study of disabled persons and the existing services and service deficiencies which are present. This provides a foundation for awareness activities. Also, included is an awareness created through publicity of the barriers to independence in the community. Public education can be accomplished through media presentations and events emphasizing the accomplishments, needs, and services for disabled persons.

Secondly, increased awareness in the community of the services of the independent living program is vital. Making disabled persons cognizant of the contributions and services provided to the community is essential to outreach. The media, brochures, publications, and other avenues may be useful in this area.

Needs assessment can be handled in a variety of ways ranging from formal surveys conducted in the community to documentation of the needs of disabled persons presenting themselves for services. The most appropriate method for the community must be determined with consideration given to cost and other factors. However, a program can be effective only if its services are responsive to the needs of the population it serves.

Communications. Communication services primarily affect visually and hearing impaired persons who are in need of reader and interpreter services. However, these services may be essential for others who are handicapped in basic communications areas. The provision of reader and interpreter services can make access to a wide variety of community services, institutions, and programs possible for these individuals.

Transportation. Transportation services are offered by many independent living programs as an adjunct to their basic program. Transportation services are often provided on an individual basis to assist handicapped persons to obtain services from the program or other community agencies. The transportation service is usually in the form of a van or bus modified to accomodate disabled passengers and is not intended to take the place of public systems. In providing direct trans-

portation services, independent living program personnel should be sensitive to equipment needs for various groups of disabled persons in order to purchase suitable transportation equipment. Henderson and Thomas (1978) provide a useful guide to equipment selection and point out the need to consider major functional problems such as spasticity, loss of balance, and visual impariment in addition to mobility impair ment. Also, equipment features such as the exterior finish (visibility), floor coverings, signal systems, suspension, air conditioning, and lifts require careful consideration.

Of considerable importance is the actual implementation of the transportation system with equipment, drivers, and schedules. In many situations the demand for transportation services has been extensive because of nonexistent or inadequate public systems. Therefore, scheduling and use become a major concern to independent living program personnel. This requires the time of program personnel and telephone access for program recipients. The cost of drivers, insurance, fuel, maintenance, equipment, and related items is a major concern for program administrators.

Social and Recreational. Although primarily concerned with referral to these services, some independent living programs have found it helpful to offer social and recreational activities to assist disabled persons in making the transition to community activities. Programs can offer these activities as an initial opportunity for some disabled individuals to meet other disabled persons in a more relaxed setting. Such services enable persons to test and/or develop social skills prior to moving out into the community. The possibilities of introducing adaptive techniques facilitating participation in recreational pursuits are also possible for hobbies, sports, and games.

Social activities planned and coordinated through the independent living program and held in other community settings is another important service. Building group cohesion through such activities may be important for other services such as advocacy and peer counseling. What must be kept in mind is the emphasis on movement to independent functioning in the social and recreational realm through a *transitional* activity conducted by the independent living program.

Other Services. Although these services may not be offered through independent living programs meeting the philosophical test for independent living, they are listed in the ILRU Registry and can assist disabled persons in living independently. Personal care services such as attendant services, food preparation services, housekeeping, residential facilities, and wheelchair or equipment repair are important. In order to live independently, some disabled persons will require one or more of

these services from community agencies. Often, the independent living program will be involved in arranging and/or advocating for these in addition to such services as financial support, medical treatment, and employment. In the situation where such services are nonexistent, the program may have to provide services on a temporary basis as some independent living programs have done. Also, the provision of employment-related services such as placement may be necessary although the use of vocational rehabilitation agencies should be encouraged if at all possible.

Summary

Independent living services represent a wide spectrum of interventions developed to meet the needs of disabled persons in the community. Although the service configurations can vary widely depending on the community, there are commonalities among the programs as revealed by the Registry maintained by ILRU. This section has provided a brief overview of the major service categories within the philosophical framework found in most independent living centers, namely that both personal skills development and community action are essential to independent living in the community. The services provided by independent living programs can be broadly grouped under the headings of information and referral, advocacy, skills development, counseling, community awareness and needs assessment, communications, transportation, and social/recreational. Advocacy is at the heart of the independent living service program and provides the framework from which many other services emanate. Also, peer counseling, an essential feature, often distinguishes independent living programs from many other programs for disabled persons.

Notes to the Trainer

Independent living programs may offer a variety of services depending on the needs of their clientele. Participants should have a general understanding of each of these services as well as an appreciation of the reasons why client advocacy is an essential feature of any program. It is important to note that independent living centers (ILC), the predominant program mode, offer services in eight categories.

Chapter 6: **Independent Living Program Personnel**

In a recent publication presenting their impressions from a nationwide study of independent living programs, Nosek, Dart, and Dart (1981) advanced three principles for staffing. These principles were:

1. The majority of board and staff members should be independence-oriented individuals with disabilities who have a sophisticated understanding of the social reality and the organizational and communication arts.
2. Criteria for selection of board members and employees should be flexible, focusing on motivation, dedication to the goals of the movement, and personal abilities as well as experience and academic qualifications.
3. Board, volunteer, and staff members should be carefully trained, with particular emphasis on learning and communicating independent living skills, mastering proven administrative and communicative systems, and utilizing the best modern management technology (p. 4).

Regarding the first principle, one should note that Part B of Title VII in the Rehabilitation Amendments of 1978 calls for substantial involvement of persons with disabilities in the policy direction and management of independent living centers. In fact, grants were not made under Part B unless programs could provide assurances of this substantial involvement of handicapped persons. Indeed, the Proposed Program Regulations (RSA, November, 1979) stated, "Every position at a Center for Independent Living should be considered as a potential training situation, so that no role is seen as an impossible one for a severely handicapped person to fill" (IRI, 1980, p. 40).

The importance of flexibility in selection criteria is clearly seen in the comments of Beverly Chapman, Director of the Center for Independent Living in Central Florida. She noted that her staff of 17 people includes "people with degrees and without degrees, with experience and some who have never been given the opportunity to fully utilize what they were taught" (Chapman, 1981, p. 43). As an example of this principle at work, Chapman cited one staff member with a third grade education who lived in an institution all her life. "She is one of our best peer counselors. We hired her because we saw what she could do, not just what she couldn't do" (Chapman, 1981, p. 43).

The final staffing principle underscores the importance of competence in whatever role one plays in an independent living program. This competence should be sought during the screening process and then

strengthened through appropriate training after the person has been hired. As Nosek. et al. (1981) noted, "Instead of looking only for formal employment experiences and technical qualifications, a particular effort should be made to recruit and provide effective training for promising disabled persons" (p. 15).

Throughout this publication, emphasis has been placed on designing independent living services to meet the needs of individuals in the community. The same point can be stated for staffing, i.e., develop an organizational structure appropriate for achieving the service goals of the program. The effectiveness of the organization must then be assessed with the following principle in mind. "The only true measure of an independent living program and its staff is the extent to which specific people are helped to become responsible and productive" (Nosek. et al., 1981, p. 4).

Experience to date with staffing of independent living programs suggests the need for some or all of the following positions (Chapman, 1981; IRI, 1980; Nosek, et al., 1981):

1. **Director**

   The Director is the administrator and chief executive of the independent living program. This person is responsible for total operation of the program including staffing, planning, program development, budgets, accountability, evaluation, public information, and other administrative responsibilities. The Director will represent the independent living program at the local, state, and national level. The Director should serve as a member of the Board of Directors and assist them in developing program policy.

2. **Administrative Support**

   Administrative support to the Director can be provided in a variety of ways. For programs with larger budgets and staffs, an *Assistant Director* may be needed. Program planning, developing, and directing as delegated by the Director will often be the responsibilities of the Assistant Director. In addition to these duties, the Assistant Director may supervise information and referral, transportation, housing, and other service areas.

   For other programs, a full or part time *Business Manager* may be needed. The Business Manager would be responsible for the financial accounting for the program. Monitoring fee for service payments, grants management, and other day to day operating activities of the program should be assigned to the Business Manager.

3. **Coordinator of Personal Care Assistance (Attendant Services)**

   The Coordinator of Attendant Services would be responsible for

all areas of attendant care including recruitment, selection, training, and placement with severely disabled persons within the geographical area of the independent living program. This person would be in charge of developing and managing the training program for attendants.

4. **Coordinator of Independent Living Skills**

   The Independent Living Skills Coordinator assists disabled persons in an individualized program of services that may include counseling, skills training, education, and referral. Many duties fall within this role ranging from design and implementation of a case managment system to liaison and outreach programs with other agencies and individuals in the community.

5. **Financial Benefits Counselor**

   The Financial Benefits Counselor provides information and counseling on financial benefits and entitlements and serves as an advocate for the client with the various funding agencies. This individual should also work with the Board of Directors to develop policy and advocacy positions regarding financial benefits.

6. In addition, other staff members may include coordinators of:
   - Independent Living Counseling (See next section, Chapter 7, on the role of the rehabilitation counselor in independent living.)
   - Employment Services
   - Peer Counseling
   - Housing
   - Transportation
   - Education
   - Special Populations (deaf, blind, etc.)

7. **Board of Directors and Advisory Committee**

   Finally, the Board of Directors of the independent living program must be considered. Although not mandated to do so, many IL programs have opted to name a Board with authority to hire and dismiss employees and to establish policies which have a major impact on the program. In other programs, the Board of Directors serves only as an advisory board with the authority remaining with the Director and/or a sponsoring agency.

   Nosek, et al. (1981) found that the average number of Board members in the programs they visited was 12 with approximately sixty percent or more having disabilities. Most of the Boards were elected by the membership of the independent living program which ensured substantial participation of consumers of independent living services in policy making.

An Advisory Committee is another resource which program directors might wish to consider. Members of this Committee could be selected based on their expertise in such areas as "funding, administrative policies, social action, and relationships with the government and other groups and agencies" (Nosek, et al., 1981, p. 13).

The value of an Advisory Committee to the program can easily be seen in the description of such a group for the Center for Independent Living in Central Florida. Consisting of 15 to 30 members, their Advisory Committee is made up of "lawyers, doctors, resource development specialists, the director of the VR program in Florida, a congressman, state representative, state senator, mayor, and a city councilman." Although their Advisory Committee does not meet, they are accessible to the director for advice and assistance (Chapman, 1981).

Summary

Staff members of an independent living program should be committed to the independent living philosophy and goals. They must have life experiences and competencies which prepare them to assist other individuals with disabilities to lead productive and rewarding lives. To meet this goal and the provisions of recent legislation, independent living programs must, therefore, ensure substantial participation of persons with disabilities on the staff, Board of Directors, and Advisory Committee. Depending on program model and services needed, additional staff may be employed in IL counseling, peer counseling, housing, transporation, education, and special populations.

Notes to the Trainer

After discussion of the principles of staffing IL programs, participants should be informed regarding the various staff positions within an independent living program. Further they should be aware of duties and responsibilities of IL staff and of the specific services they are to provide. Since ILR is a new service, positions and duties will vary from program to program.

Chapter 7: **The Role of the Rehabilitation Counselor in Independent Living**

Title VII (Parts A & B) of the Rehabilitation, Comprehensive Service, and Developmental Disabilities Amendments of 1978 provide both a justification and definition of the role of the independent living counselor.

Under Part A of Title VII, the legislation requires state plans to provide assurances that (1) an individualized written rehabilitation program will be developed for each handicapped person, (2) services will be rendered in accordance with the plan, and (3) periodic reviews of the individual's progress will be conducted. In Part B, three general functions of the rehabilitation counselor in independent living—intake counseling (needs assessment), referral, and advocacy—are described.

A synthesis of these legislative requirements suggests that the rehabilitation counselor must have commitments and/or skills in the areas of normalization, human and legal rights, interpersonal communications, and individual program planning.

Normalization: The Philosophy of Independent Living

The counselor must be aware of the contrast between the traditional rehabilitation model and the independent living model (DeJong, 1979). Too often, the rehabilitation paradigm has overemphasized the need for the individual to change in response to professional advice. Since the person's problems are viewed mainly as deficiencies in personal functioning which can be overcome through some "prescribed therapeutic regime" (DeJong, 1979, p. 442), the danger in the rehabilitation model is that the individual becomes an object to be "fixed" rather than an active participant in the helping process.

The independent living paradigm, on the other hand, views the environment as the primary source of the person's problems. By reducing certain physical and social barriers, the counselor can minimize many of the limitations experienced by individuals with severe disabilities. Environmental factors which create problems for individuals with disabilities are (Trieschmann; cited by DeJong, 1979):

1. The hospital milieu
2. Stigma value of disability
3. Family and interpersonal support
4. Financial security

5. Social milieu
6. Urban versus rural residence
7. Access to medical attention and equipment repair
8. Access to education, recreation, and avocational pursuits
9. Socio-economic status
10. Architectural barriers
11. Availability of transportation
12. Legislation
13. Cultural and ethnic influences

As an advocate for social and environmental change, the rehabilitation counselor in independent living must conduct community information and education programs, work with legislators, and communicate the implications of legislation to employers and other affected groups.

Human and Legal Rights

Protection and advocacy regarding a person's human and legal rights is another significant component of the independent living counselor's role. Arenas in which this protection is needed include both social and human service settings. For example, in the social area, individuals with disabilities have the right to . . .

1. Make contracts
2. Hold professional, occupational, or vehicle driver's licenses
3. Make a will
4. Marry
5. Adopt or bear children
6. Hold and convey property
7. Access to publicly owned or financed buildings, publicly used but privately owned buildings, public streets, sidewalks, and transportation facilities and rolling stock
8. Equal educational opportunity in the least restrictive and denormalizing environment as possible
9. Equal employment opportunity
10. Just payment for labor
11. Equal access to medical services (Rigdon, 1977)
12. Vote and participate actively in political affairs.

Because of their need for comprehensive services, individuals with severe disabilities may also need advocacy assistance with multiple social agencies. Cull and Levinson (1977) identified numerous rights of individuals who are involved in transactions with human service agencies, e.g., clients of human service agencies have the right to:

---

1. *An explanation of the goals, functions, procedures, and operations of the agency*

2. *Referral and advocacy in instances where the agency contacted can not help*
3. *An explanation of the appeal process*
4. *Full partnership in the selection of service providers and placements*
5. *Periodic review of the plan and modification, if needed, in the intermediate and long-range program objectives*
6. *Access to agency generated material related to the client*
7. *Prompt evaluation, eligibility decisions, and services*
8. *Advocacy services on their behalf*
9. *Free expression of views regarding the quality of their program*
10. *High quality professional attention throughout the service process.*

Communication Skills

The assertive skills needed to be a good advocate are only part of the counselor's role The counselor must also have sound communication skills. Recent research (Carkhuff, 1972, 1980) indicates the effectiveness of interpersonal skills training with a variety of individuals. Bozarth and Rubin (1975) reported that higher rehabilitation counselor levels of interpersonal skills were related to greater (a) client vocational gains, (b) monthly earnings at follow-up, (c) positive psychological change, and (d) job satisfaction.

Over time, the concept of interpersonal skills has evolved from core conditions—empathy, warmth, and genuineness—to attending, responding, personalizing, and initiating (Carkhuff, 1980). Use of these helping skills enhances the probability that the goals which guide case management services are pressing, genuine concerns of the individual seeking services.

Case Management Skills

Part A of Title VII in the Rehabilitation Amendments of 1978 identified several phases of case management . .

1. Development of an individualized written rehabilitation program
2. Provision of services according to the plan, and
3. Review of the individual's progress toward program goals.

Part B underscored the need for an efficient outreach, intake, and referral system. Hence, as a case manager, the independent living counselor must be a case finder, needs analyst, goal attainment specialist, and support system designer.

Efficient utilization of program resources requires a steady flow of

individuals seeking the services of the independent living program, hence, the counselor must be a case finder. For example, counselors should develop a system for regular notification from vocational rehabilitation of those individuals who were considered ineligible or who were not successful in completing their programs. Other potential referral sources include

1. Local physicians and hospitals
2. Physical therapy and/or occupational therapy organizations
3. Social services
4. Private and state employment agencies
5. Social security
6. Self-referral
7. Friends and/or relatives
8. Churches
9. Community organizations
10. Home health teams
11. Public and private schools

To understand concretely the potential problems of individuals seeking services, the rehabilitation counselor in independent living must also be a competent needs analyst. One approach to needs assessment reflects the research of Sigelman, Vengroff, and Spanhel (1979) who determined that disability alters human functioning and performance in any or all of the following five areas: health, social-attitudinal, mobility, cognitive-intellectual and communication functions. With the inclusion of the individual's financial situation, these five areas of human functioning could be used to structure an intake interview (Roessler, 1980(a), 1982).

The independent living counselor must also function as a service arranger, provider, and coordinator. Recent surveys identify the services needed by individuals with severe disabilities. For example, Clowers and Belcher (1978) noted that some of the most frequently requested services by severely disabled people include transportation for work, attendant care, home modification, and speech therapy. As a result of an evaluation of ten independent living centers in California, Stoddard (1980) reported that the following were the most frequent service-related requests, counseling, other places to get help, attendant care, get a ride, talk to people with similar disabilities, find a new place to live, and meet people. The previous section on independent living services provided additional detail on the many concrete services which the independent living counselor can arrange for or provide.

Independent living rehabilitation counselors must also have an understanding of the factors which encourage or impede goal-oriented

behavior. For example, goal attainment is enhanced if the counselor

1. *Starts with the most immediate, pressing needs expressed by the person.*
2. *Determines the person's personal expectations regarding goal attainment. If those expectations are negative, the counselor should ascertain the reasons for the negative expectations. In some cases, they may feel they understand the steps but have a low probability of succeeding. The counselor must understand how strategies such as guided practice, modeling, feedback, encouragement, and reinforcement can be used to deal with negative expectations.*
3. *Breaks the goals into smaller compatible sub-goals for which effort on the person's part can be reinforced.*
4. *Demonstrates the relationship of the smaller steps to overarching goals of a more independent and fulfilling life.*
5. *Points out instances of success to reduce the person's level of stress and build expectations of goal success.*
6. *Identifies feasible responses to barriers in the physical, social, financial, and/or human service environments (Locke, Saari, Shaw, & Latham, 1981; McDaniel, 1976; Roessler, 1980(b); Sands & Kraus, 1975; & Zane, 1961).*

The counselor must also monitor the individual's progress carefully. Progress can be determined by estimating the extent to which the gap between the person's initial status and the expected outcome closes over time. Of course, many factors can affect the person's progress. For example, the counselor needs to learn whether the individual

1. is actually following the steps of the plan
2. is on schedule in achieving certain intermediate gains related to the overall goal
3. still views the program as something he/she wants and needs.

Before terminating formal contact with the person, the independent living counselor should determine which needs have been met and which require some long-term support. For example, the individual may have developed certain self-care skills, received certain equipment and/or housing modifications, and developed additional recreational outlets. At the same time, continuing need may exist for financial maintenance, transportation, attendant care, equipment repair, and communication support from interpreters or readers. Therefore, the independent living counselor should place high priority on establishing a functional, long-term support program designed so that the person and/or spouse and family can implement it with little outside assist-

ance Creation of such a program would signify the end of active involvement by the counselor except for periodic follow-up, e.g., annually, with the person.

Summary

Playing a crucial role in the overall service program, the independent living counselor must be committed to the independent living philosophy and to advocacy for individual legal and human service rights In addition, the counselor must be proficient in interpersonal and case management skills. As case managers, counselors are involved in case finding, needs analysis, goal attainment, and support system designing. Evidence of the application of these case management skills should be clearly documented in the case file of individuals receiving independent living services.

Notes to the Trainer

Advocacy is again a critical theme particularly as it results in the removal of handicapping aspects of the environment. By the same token, participants should not lose sight of the many other important commitments and activities of the rehabilitation counselor in independent living This section should be presented as a brief overview of the "role and function" of the rehabilitation counselor in IL settings.

Chapter 8: **Evaluation of Independent Living Outcomes**

Muzzio, LaRocca, Koshel, Durman, Chapman, and Gutowski (undated) provided some excellent reasons for evaluating independent living programs. Results of such assessments can:

1. *Justify the existence of independent living rehabilitation,*
2. *Justify the level of expenditures for the program,*
3. *Improve techniques of independent living rehabilitation, and*
4. *Insure that services are being delivered to the target population.*

Due to the ambiguity regarding desirable outcomes in independent living rehabilitation, evaluation of such programs is no easy task. As Muzzio, et al. (undated) and Darley, Tate, and Frey (1979) noted, no single success criterion exists. Instead, multiple criteria of success must be employed. The importance of a variety of criteria are reflected in the following pertinent program evaluation questions:

1. Are program services increasing the functional capabilities of individuals with severe disabilities?
2. Is the program initiating changes in the environment which enhance the freedom of individuals with severe disabilities?
3. Are clients satisfied with the services of these programs?
4. Are programs managed effectively and efficiently?

Person Change

In discussing "person change" through independent living services, Stoddard (1980) noted several important areas—self-image as a disabled person, functional limitations, and a variety of social and personal skills. Sigelman, et al. (1979) further elaborated on target areas by defining five dimensions of human functioning, e.g., health, social-attitudinal, mobility, cognitive-intellectual, and communication. Because it is based on an exhaustive review of the literature, the Sigelman, et al. (1979) scheme provides a comprehensive outline for understanding human functioning and, thus, for establishing person change goals for independent living services. In each of the five functioning areas, independent living services could be designed to:

Health functions

Increase the overall physical health of the individual
Decrease impairments in bodily systems
Decrease the amount of pain experienced
Increase the individual's participation in life activities

Social-attitudinal functions

Increase the individual's manual skills for manipulating objects and devices

Increase the individual's capability to move at home, work place, and from place to place in the community

Decrease the individual's difficulty in participating in other physical activities

Cognitive-intellectual functioning

Increase the individual's intellectual capacity to manipulate symbols and objects

Increase the individual's capability to acquire or store in memory new cognitions and behavior patterns and/or to transfer learning to new situations

Communication functioning

Decrease the individual's difficulties in sending and receiving messages

Decrease the individual's difficulty in exchanging information and ideas with other persons.

(Sigelman, et al., 1979)

Stating goals in these areas only sets the stage for evaluating a program's effectiveness. The next step involves specifying measurable objectives which include statements of the performance or behaviors expected. Positive changes in these behaviors or performance levels as a result of services then provides evidence for the effectiveness of the program.

Although they have utilized different categories than Sigelman, et al. (1979), several individuals have developed multi dimensional rating scales and behavioral checklists adaptable to program evaluation in independent living. Examples of these multi-dimensional instruments include the ***Level of Rehabilitation Scale*** (Carey & Posavac, 1977), ***Independent Living Assessment for Persons with Disabilities*** (Schwab, 1981), ***Functional Assessment Profile*** (Ehrenworth, Kelly, Langton, LaRue, Marsh, Rapp, Reilly, & Konar, 1980), ***Independent Living Behavior Checklist*** (Walls, Zane, & Thvedt, 1979), ***Functional Assessment Inventory*** (Crewe & Athelstan, 1980), ***The Ideabook: 550 Indicators for Use in Setting Goals*** (Garwick & Brintnall, 1977), and ***Functional Capacity Areas*** (Crumpton, Cassell, Freeman, & Sawyer, undated).

Environmental Change

Historically, efforts in rehabilitation have primarily reflected the medical model which emphasized the need to change or "cure" the

individual. The limitations resulting from disability were viewed as properties of the person which could be worked around or removed by restoration, counseling, or training services. In recent years, this "person" focus has given way to a more comprehensive model of disability and its effects. As Sigelman, et al. (1979) pointed out, functional capacities may or may not constitute handicaps depending on the nature of the environment.

In discussing problems emanating from the physical environment, Muzzio, et al. (undated) stressed that, in the past, few, if any, programs have worked to create adaptive barrier free housing, accessible and affordable transportation, barrier free public/private facilities, and special communication and information services. Because of the lack of these services, individuals with physical and sensory disabilities are denied access to full participation in society in many ways.

Independent living programs could undertake programmatic efforts in any or all of these problem areas—housing, transportation, public and private facility accessibility, and communication and information services. Outcomes in these areas could be monitored in terms of the concrete objective sought, date to achieve the objective, number of services or service contacts required, amount of time devoted, cost of services, problems encountered, completion date, and actual outcome.

In the housing area, outcomes such as housing referral directories, number of home inspections, number and type of home modifications, and referrals to other agencies for housing assistance could be monitored (Stoddard, 1980). Effects of efforts to initiate needed legislation or financial benefits for housing modification services could also be assessed. Wright (1979) cited several outcomes needed in the housing modification area, e.g., availability of (1) home evaluation teams to assess housing needs, (2) quality design and construction experts to assist in housing modifications, (3) funds for making needed changes, and (4) training of independent living personnel to conduct home evaluations. Of course, several of the above recommendations overlap needed changes in the economic or human service environments.

According to Turem and Nau's (1976) Comprehensive Needs Study, the greatest concern of severely disabled people is "getting from point A to point B." Part of this problem could be resolved by modification of the home itself, e.g., elimination of stairs and redesign of the kitchen and bathroom areas. But, another facet of the mobility issue is public transportation. Independent living programs should concentrate on specific objectives such as developing a subsidized and properly staffed van service, decreasing problems involved in getting to public transportation areas, providing a secure, safe place to wait for transportation;

and relieving problems in getting on and off public transportation.

Plans for changes in the social environment should be described in a community impact statement (DeJong & Hughes, 1980). Through advocacy and community education efforts, programs in independent living could do much to reduce stigma and prejudice against individuals with disabilities. Efforts of these programs could be evaluated in terms of number of people reached, changes in audience attitudes, problems identified and resolved, and indications of increased involvement of people with disabilities in society. Problems identified and resolved may fall in legal, financial, employment, and social areas. Organizations affected might include state and federal agencies, county and municipal offices, state and federal legislatures, and private employers or community groups. Clear evidence of the effectiveness of these programs would be increased options and benefits within the social environment, e.g., jobs, social activities, services, and financial benefits.

Negative environmental effects stem from insufficient financial support and economic disincentives. Gaps in financial coverage for the needs of severely disabled individuals have historically resulted in poor or non existent attendant care, medical, transportation, and housing modifications services. Hence, severely disabled people have subsisted on a narrow economic base. Moreover, financial disincentives resulting from returning to work confine these individuals to this narrow economic base. For example, Social Security benefits for maintenance and medical services are decreased or eliminated if the individual becomes employed.

In the economic sphere, programs in independent living have several responsibilities. The first, of course, is to the individual. Through financial counseling, program staff should help the individual increase his/her economic base. Outcome criteria could include considerations such as increases in monthly financial support and number of agencies providing assistance. Moreover, programs could demonstrate that, as individuals are provided resources to live independently, costs in other areas such as institutional care decrease.

Secondly, program efforts should be directed toward initiating legislation to increase financial benefits needed for transportation, housing modification, attendant care, and medical services. For example, Frieden and Frieden (1980) reported on a program in Sweden which provides up to $10,000 for a one-time housing modification. Finally, programs must work on eliminating certain financial disincentives for returning to work such as those in Social Security. Results of interest in the legislative area include number of people contacted, types of

legislation written and sponsored, type and number of existing provisions changed, and economic benefits available in new legislation.

Gaps in human services for severely disabled people were implicit in the preceding discussion of physical, social, and economic factors As Muzzio, et al. (undated) indicated, too few service programs exist to provide adaptive barrier free living, accessible and affordable transportation, barrier free public and private facilities, and specific communication and information services. In addition to these problems, economic deficiencies and disincentives confine severely disabled individuals to a narrow economic base and to limited services in attendant care and medical services.

Advocacy and community education efforts are continually needed to encourage human service agencies to establish new service programs. Positive outcomes of efforts to change the human service environment might include (a) number of successful linkages with service agencies, (b) new service components initiated, and (c) problems identified and resolved in securing new services.

Client Satisfaction

Multiple problems have been identified with assessment of participant satisfaction. In fact, Scheirer (1978) stated that a basic proposition for interpreting satisfaction data is as follows. "Participants like social programs, evaluate them favorable, and think they are beneficial, irrespective of whether measureable behavioral changes take place toward stated program goals" (p. 55).

And yet, other authors (Larson, Attkinsson, Hargreaves & Nguyen, 1979) have stated valid reasons for securing client satisfaction data. With consumer ratings of the program, the researcher avoids biasing results "toward the provider's or the evaluator's perspective" (p. 197). Moreover, data on consumer outlook is required for many programs by federal legislation. This requirement reflects the importance attached to providing those individuals who typically are somewhat powerless in society with a voice in policy development and program direction. Finally, Reagles, Wright, and Butler (1970) described client satisfaction as a function of the degree to which services meet the consumer's needs.

Client satisfaction measures can be specifically developed for the assessment of services in an independent living center. Areas that might be tapped include the ease of contacting and finding the independent living center, the extent to which the center and its employees are able to help the individual, the extent to which workers can identify other valuable resources, the speed with which services are provided, the adequacy of services, and overall satisfaction with the

attitudes of the staff and the help received (Cook, 1977, Roessler & Mack, 1975). However, pilot studies will be required to establish the reliability and validity of these measures.

A good case can also be made for a standardized measure of client satisfaction yielding normative data regarding performance of similar programs. With its reliability and validity established in prior research, the instrument could be used with some degree of confidence. Table 2 presents items for one such instrument developed by Attkinsson, Larson, Hargreaves, and Nguyen (1979).

Table 2

Sample Items from the Client Satisfaction Questionnaire (CSQ)

1. *How would you rate the quality of service you received?*
2. *Did you get the kind of service you wanted?*
3. *To what extent has our program met your needs?*
4. *If a friend were in need of similar help, would you recommend our program to him/her?*
5. *How satisfied are you with the amount of help you received?*
6. *Have the services you received helped you to deal more effectively with your problem?*
7. *In an overall, general sense, how satisfied are you with the service you received?*
8. *If you were to seek help again, would you come back to our program?*

Project Operation. Program evaluation of independent living centers should also focus directly on project operations. The major consideration is the extent to which management is operating effectively and efficiently in accomplishing project goals and objectives. For example, were programs implemented as projected, e.g., peer counseling, transportation and housing referral, equipment repair, etc., and are they performing as expected?

Another significant concern is the extent to which the program is serving the appropriate target groups (Mazzio, 1981). Client data such as age, education, diagnostic category, and severity of disability can be used to demonstrate that the program is serving severely disabled individuals who are overlooked by other human service programs.

A list of specific project operation criteria was developed by the New York State Office of Vocational Rehabilitation (1979). To assess the operation of its independent living programs, the New York agency focused on dimensions such as the (1) number of handicapped individuals on staff, (2) movement of handicapped staff and clients to jobs or

positions outside of the center. (3) extent to which severely disabled consumers play a role in policy making. (4) number of handicapped individuals on the Board of Directors and advisory committee; (5) level of staff performance, retention, and staff turnover; (6) progress toward non federal grant support, e.g., commitments from private foundations, development of fee for service agreements and third party agreements, fund raising, decrease in grant support required for continuation, and (7) service components developed—individual group counseling, ADL training, mobility training, and personal adjustment training and number of clients served by each (New York State Office of Vocational Rehabilitation, 1979).

Other facets of center operation could also be monitored. Information regarding the most effective and cost efficient staffing patterns for centers would be valuable Centers should also keep track of the units of service rendered, the cost of the various services, and the extent to which different funding sources contributed to individual service costs (Muzzio, et al., undated) Other data of importance include the number of individuals served, the kinds of disabilities served, the number of referrals made to other agencies or providers, the number accepted in those programs, and the number for whom services were not provided (Arkansas Division of Rehabilitation Services, 1980).

Summary

Evidence of the success of independent living services should be sought in terms of (a) client functioning, (b) environmental changes, (c) client satisfaction, and (d) program management practices. Regarding person change, emphasis is on human capacity areas such as health, social attitudinal, mobility, cognitive-intellectual, and communication functioning. To eliminate external barriers to life satisfaction, environmental changes are needed in physical, social, economic, and human service areas Accomplishments of person and environment changes should enhance the client's satisfaction with program services Finally, independent living programs should also be evaluated as to their overall management capabilities.

Notes to the Trainer

The purpose of this section is to identify concrete indicators of the effects of services provided by independent living programs. These evaluation criteria also clarify goals and objectives for independent living programming As a result of this section, participants should gain an understanding of objectives in the areas of client change.

environmental change, and client satisfaction that are appropriate for evaluating independent living programs.

Unit III
Independent Living in Vocational Rehabilitation

Chapter 9: VR/ILR Collaborative Efforts

The 1978 Amendments (PL 95-602) delegate responsibility for comprehensive services for independent living to state rehabilitation agencies.

Title VII of these amendments authorizes a state grant to be administered by state vocational rehabilitation agencies to serve the severely handicapped. Special funds are to be used for operation of centers for independent living, services for older blind persons, and protection and advocacy services.

Options for State Rehabilitation Agencies

In administering independent living rehabilitation (ILR) programs, state rehabilitation agencies may exercise one of several different options. They may:

1. Integrate ILR within the present ongoing vocational rehabilitation (VR) program. ILR services would be provided through the traditional VR service delivery system.
2. Establish a separate agency within VR with its own service delivery system, administrative staff, and personnel.
3. Contract with a private agency to operate the ILR program.
4. Contract with a consumer organization to provide ILR services.
5. Permit another public agency to operate the ILR program.

Title VII of the 1978 Amendments requires that 20% of the rehabilitation agency's Part A funds (when appropriated) be allocated to local, public, or nonprofit private agencies.

Under Part B of Title VII (which is funded) state agencies may receive grants to establish independent living centers. However, agencies must apply within six months of the availability of these grants. If not, RSA may grant funds to local, public, and/or private nonprofit agencies. Another option open to the agency is to subcontract operation of the center to another agency but before doing so the state agency must have assurances that handicapped persons will have a major voice in policy development and management of the center.

Overall, legislation stipulates that severely handicapped individuals have "substantial" involvement in operation of independent living programs. Severely handicapped persons must be employed in the program, and the state plan will need to specify how this will be done.

Independent Living Clientele

A recent survey cited by DeJong (1979) indicated that there are

approximately 6.8 million persons in the United States with severe disabilities who are unable to perform major activities related to independent living. Expanding this population to other individuals who are unable to carry out most major activities increases the potential independent living clientele even further.

Eligibility

Independent living services are designed primarily for individuals who have been considered by vocational rehabilitation as too severely disabled to benefit in terms of employability. Independent living services have several purposes:

1. To improve or maintain the ability to function more independently in family and community rather than to achieve a vocational goal; or
2. To assist a severely handicapped individual to "engage or continue in employment" (PR 11/29/79, 1363).[1]

According to the Rehabilitation Services Administration, eligibility is to be determined to the greatest extent possible on existing case record information. Diagnostic studies for eligibility determination will be conducted only where "absolutely essential" (PR-1363.31). A Certificate of Eligibility or Ineligibility will be completed and reviewed similar to that of the vocational rehabilitation program (PR 1363.32).

Special priority is to be given to severely handicapped individuals, including the homebound, who are not receiving vocational rehabilitation services, institutionalized individuals, and individuals in danger of becoming institutionalized. The Commissioner may at various times identify other specific disability groups to receive these services on a priority basis (PR 1361.34).

Independent Living Services

Reviewed in Unit II, Section B, independent living services include:

1. **Intake counseling** to determine the severely handicapped individual's need for specific independent living services;
2. **Attendant referral and counseling services;**
3. **Advocacy;**
4. **Attendant care training;**
5. **Peer counseling;**
6. **Independent living skills training;**
7. **Housing and transportation referral and assistance;**

---

[1] PR 11/29/79, 1363 refers to Rehabilitation Services Administration Regulations, November 29, 1979, Section 1363.

8. **Surveys and directories regarding housing, transportation, and support services;**
9. **Health maintenance programs;**
10. **Group living arrangements;**
11. **Education and training;** and
12. **Social and recreational assistance.**

When an independent living program cannot provide all of the listed services, every effort should be made to provide the following core services:

1. *Information and Referral Services (IR)*
2. *Attendant Care Services*
3. *Housing Referral Services*
4. *Peer Counseling*
5. *Financial Benefits Counseling Services*

Closure and Follow-up

Criteria for closure have not been established and will need clarification through legislation, regulations, and guidelines. Some services may be provided on a one time basis such as housing modifications while others may be ongoing such as attendant care, peer counseling, and medical care. The counselor should, therefore, identify and justify those areas of ongoing need in an Independent Living Plan [1] and assist the consumer in securing similar benefits to the extent possible to meet those needs.

Closure in independent living implies satisfaction of certain short-term needs as well as a definite plan including financial resources (Similar Benefits) for meeting long-term needs.

Without an adequate plan for meeting those long-term needs, the client will be unable to sustain a more independent living situation, and the initial program gains will be lost.

Individualized planning and case recording should be provided for each client to insure that the person's needs are being met. Reviews should be made on a regular basis to evaluate the services in terms of client needs in such areas as equipment, household management, housing, attendant care, recreational, psychological, transportation, and medical maintenance.

Data for monitoring individual outcomes could be collected as a

[1] The Independent Living Plan is analogous to the IWRP used by vocational rehabilitation agencies and the IEP used by educational institutions.

regular part of the case management process and recorded in the case file. With this case information, independent living rehabilitation staff should be able to document the extent to which the individual has met pressing needs: developed functional capacities and skills: established procedures and support for meeting ongoing needs: become ready for alternative community living arrangements. vocational rehabilitation services. and/or employment: and gained greater access to a barrier free environment.

VR/ILR Relationships

Freedom of movement between VR and ILR. and vice versa. will be essential. For example. given its emphasis on severe disabilities. VR will have many referrals who will be able to benefit from independent living services. Some individuals may need to be transferred to the ILR Program during the course of vocational rehabilitation. Conversely. many ILR clients will develop vocational feasibility with time and need VR services in order to enter/reenter gainful employment.

Important considerations for enhancing the VR/ILR linkage include development of methods of monitoring client status and service outcomes so that program referrals can be made between VR and ILR. supervising counseling personnel in both programs. allocating case service funds to both phases of the program. and identifying client outcomes for purposes of program evaluation. As one means of coordinating VR/ILR efforts. state rehabilitation agencies could use Part A funds to purchase client services from Part B centers.

If independent living rehabilitation services are to be successful. it will be necessary that program administrators. personnel. service providers. consumers. and consumer advocates develop and maintain good communication linkages. Coordination. cooperation. and compromise on the part of all concerned will be essential components of the program.

Summary

Parts A and B of Title VII (1978 Amendments) provide bases for two approaches to independent living services. Under Part A. state vocational rehabilitation agencies are to develop a state plan for agency provision of ILR services. States may elect to follow one of five different models for delivering these services.

Part B calls for the development of independent living centers established by vocational rehabilitation agencies either directly or by subcontract. If state agencies take no action to develop such a center. they can expect the Rehabilitation Services Administration to sub-

contract with another agency in the state for the services

Independent living services through Part A or B are specifically reserved for severely disabled individuals who are not receiving vocational rehabilitation services and are in danger of becoming institutionalized. A core program of services for these individuals would include information and referral, attendant care and referral, housing referral, peer counseling, and financial benefits. These services should not be terminated until it is apparent that the client has sufficient skills and support to function more independently.

The success of the independent living movement depends on close collaboration among all parties involved—VR and IL administrators and service providers, consumers, and consumer advocates. Many individuals seeking rehabilitation services can profit from coordination between VR and ILR service systems.

Notes to the Trainer

This section reviews the rationale for the ILR services to be provided by state vocational rehabilitation agencies. Hence, participants should understand (a) the forms by which these services are to be provided, (b) the need for policy clarification regarding such issues as eligibility and closure in ILR, and (c) their own role in contributing to the success or failure of independent living rehabilitation.

Chapter 10: **Continuing Issues**

The preceding chapters have introduced many important topics in order to facilitate the reader's understanding of independent living and the relationship of it to vocational rehabilitation. As in any new program, many issues continue to face program planners and service delivery personnel. Resolution of these issues requires development of new policies, procedures, and services. This publication closes by briefly highlighting a number of important concerns in independent living.

The following issues were identified in the preparation of the first nine chapters and in a review of other issue papers and documents (See in particular DeJong and Hughes, 1980). In order to present the issues in the most coherent fashion, they have been grouped in six areas: (1) services and staffing, (2) vocational rehabilitation/independent living cooperative programming, (3) organization and administration, (4) funding, (5) planning, evaluation, and accountability, and (6) consumer involvement and community participation. The issues have been phrased in the form of questions to stimulate discussion leading to identification of alternative solutions or recommendations.

1. **Services and Staffing**
   - How can peer counseling services be provided most effectively?
   - What range of services should independent living programs provide, and what are the central, core services?
   - What eligibility considerations, if any, should be used?
   - Should services to family members be included?
   - What services should be provided directly and what services should be purchased?
   - How can basic terminology regarding independent living be clarified (e.g., What does independent living mean? What does peer counseling mean? What are independent living services?)?
   - What are the best ways of providing and/or arranging for attendant care services?
   - How should independent living program staff be trained? What types of preservice training should the staff have?
   - What new types of services are needed or will be needed to meet new demands?
   - How can advocacy services be provided in the most optimal manner without excessive organizational conflicts?
   - What standards for staff performance should be imposed?
   - How should the priority for the employment of disabled staff be operationalized?

2. Vocational Rehabilitation/Independent Living Cooperative Programming

- How can the requirement for the state plan for independent living be met in the most effective manner?
- How can the potential and, or real conflicts between the requirements for consumer involvement and statutory responsibilities of state agencies be resolved?
- How much direct control should state vocational rehabilitation agencies have over the operation of independent living programs?
- How can an effective mix of functions be developed between state agencies and independent living programs (e.g., the state agency assume planning and development functions while the independent living program assumes service provision functions.)?
- How effective can state agencies be in advocating for independent living services and funding within existing governmental structures?
- How effective can state agencies be in advocating for independent living services or funding with other state agencies?
- What techniques can be implemented to maintain or initiate ongoing cooperative relationships between state agency and independent living program staff?

3. Organization and Administration

- How can the state agency and independent living program be integrated most effectively?
- Should there be separate tracks for independent living and vocational rehabilitation within the overall state agency structure?
- What are the most effective systems for conducting needs assessments to determine the organizational structure and services of independent living programs?
- What are the most appropriate financial management procedures?
- What methods for case planning and case recording should be developed?
- Should there be a concern over opening and closing cases, or should all cases be maintained on a continuing basis?
- What qualifications should the director or principal administrator possess?

4. Funding

- How can the financial base be diversified to insure greater funding stability?

- What additional interagency agreements can be developed to maximize the use of other funds such as Title XIX?
- How can independent living programs use public funds without compromising consumer involvement, advocacy, and other key programming features?
- How can state and municipal funds be used?
- Can state agencies provide IL centers with block grants rather than pay on a fee-for-service basis?

5. Planning, Evaluation and Accountability

- What are the most appropriate models for program evaluation?
- What should be the role of state and federal agencies in the development of program evaluation and accountability standards?
- Should the evaluation system be a consumer-specific system such as that used in the vocational rehabilitation program?
- Should the use of a form such as the IWILP (Individual Written Independent Living Program) be implemented?
- How can computerized information systems be most effectively used for accountability?
- What cost effectiveness data should be gathered?
- What outcome measures should be used?
- How should staff be trained to conduct planning, evaluation, and accountability activities?

6. Consumer Involvement and Community Participation

- What techniques are most appropriate for the use of policy consultation groups?
- How can advisory groups be used most effectively?
- What structure will allow maximum participation by consumers in the policy development and decision making activities of independent living programs?
- How can equity of representation among different consumers and consumer groups be maintained?
- What training programs are available for board or advisory group members?
- What should be the mix of membership on the board between disabled and nondisabled persons?
- How can community members, volunteers and community service groups be involved in the planning and implementation of independent living programs?

These and other issues highlight the need for continuing dialogue between vocational rehabilitation and independent living program staff. The resolution of many of these issues will require planned,

systematic initiatives involving state agencies, independent living program staff, consumers, and consumer advocates.

Summary

A number of issues have been presented for review and discussion that must be clarified in the coming years. However, this does not mean that independent living programs should not proceed based on the best information and thinking available. The current era is an exciting, developmental phase in which many ideas and practices can be tried out and shared so that all programs can evolve more effective service delivery systems. The experience gained by all involved parties will be invaluable in devising workable solutions and policies for the future.

Notes to the Trainer

Brainstorming solutions to the many issues involved in implementing independent living represents a valuable closing activity for this training program. Based on their experience in human services, participants will have many possible suggestions for future ILR practices and policies.

References

References

Arkansas Division of Rehabilitation Services. Little Rock, AR. 1980.

Bozarth. J. & Rubin S. Empirical observations of rehabilitation performance and outcome Some implications. **Rehabilitation Counseling Bulletin,** 1975. **19**(1). 294-299.

Carey. R. & Posavac. E. **Manual for the Level of Rehabilitation Scale.** Park Ridge. IL. Office of Evaluation and Research Services. Lutheran General Hospital. 1977.

Carkhuff. R. **The art of helping IV** (4th ed.). Amherst. MA. Human Resource Development Press. 1980.

Carkhuff. R. The development of systematic human resource development models. **The Counseling Psychologist,** 1972. **3**(3). 4-11.

Chapman. B. Independent living. Example of an ongoing project. In T Milligan (Ed). **Implementing independent living centers.**Conference Proceedings. Hot Springs. AR. Region VI Rehabilitation Continuing Education Program. Feb.. 1981.

Clowers. M.. & Belcher. S Service delivery for the severely disabled individual Needs and services. **Journal of Applied Rehabilitation Counseling,** 1978. **9**(3). 108-115.

Clowers. M., Haley. D.. Unti. W.. & Feiss. C. **Report: Independent living rehabilitation project, final report** (Grant No. 1391-NGF-17678). Olympia. WA. Department of Social and Health Services. 1979.

Cole. J.. Sperry. J . Board. M . & Frieden. L. **New options training manual.** Houston. TX. The Institute for Rehabilitation and Research. 1979.

Cook. D Guidelines for conducting client satisfaction studies. **Journal of Applied Rehabilitation Counseling,** 1977. **8,** 108-114.

Crewe. N & Athelstan. G. **Functional Assessment Inventory.** Minneapolis. MN: University of Minnesota. 1980.

Crumpton. C.. Cassell. P , Freeman. A.. & Sawyer. H. **Functional Capacity Areas.** Knoxville. TN. Knoxville Area Comprehensive Rehabilitation Consortium. Inc.. undated.

Cull. J. & Levinson. K. The rights of consumers of rehabilitation services. **Journal of Rehabilitation,** 1977. **43**(3). 29-32.

Darley. O.. Tate. D.. & Frey. W **Issues in independent living.** East Lansing. MI. University Centers for International Rehabilitation. Michigan State University. 1979.

DeJong. G. **The movement for independent living: Origins, ideology, and implications for disability research.** East Lansing. MI University Centers for International Rehabilitation. Michigan State University. 1979.

DeJong. G. & Hughes. J. **Report of the Sturbridge Conference on independent living services.** Boston. MA. Medical Rehabilitation Research and Training Center. Tufts New England Medical Center. 1980.

Ehrenworth. J.. Kelly. A.. Langton. M.. LaRue. A.. Marsh. S.. Rapp. J.. Reilly. J.. & Konar. V. **Functional Assessment Profile (FAP): User's Guide.** Boston. MA. Massachusetts Rehabilitation Commission. 1980.

Frieden. L.. Frieden. J.. & Laurie. G. **Living independently: Three views of the European experience with implications for the United States.** New York. NY: World Rehabilitation Fund, 1980.

Frieden. L.. Richards. L.. Cole. J.. & Bailey. D. **ILRU source book.** Houston. TX. The Institute for Rehabilitation and Research. 1979.

Garwick. G. & Brintnall. J. **The ideabook: 550 indicators for use in setting goals.** Minneapolis. MN. Program Evaluation Project. 1977.

Henderson. W. & Thomas. D. Equipment selection for systems transporting the elderly and handicapped. In **Transportation for the elderly and handicapped: Programs and problems.** Washington. DC U.S. Department of Transportation. December. 1978. 127-130.

Implementation of independent living programs in rehabilitation. Seventh Institute on Rehabilitation Issues. Arkansas Rehabilitation Research and Training Center. Arkansas Rehabilitation Services. 1980.

Larson. D.. Attkinsson. C.. Hargreaves. W.. & Nguyen. T Assessment of client/patient satisfaction. Development of a general scale. **Evaluation and Program Planning,** 1979. **2**(3). 197-207.

Locke. E.. Saari. L.. Shaw. K.. & Latham. G. Goal-setting and task performance. 1969-1980. **Psychological Bulletin,** 1981. **90**(1). 125-152.

McDaniel. J. **Physical disability and human behavior** (2nd ed.) New York. NY: Pergamon Press. 1976.

Muzzio. T. Program evaluation for independent living programs In T. Milligan (Ed.). **Implementing independent living centers.** Confer

ence Proceedings. Hot Springs, AR. Region VI Rehabilitation Continuing Education Program. Feb., 1981.

Muzzio, T., LaRocca, J., Koshel, J., Durman, E., Chapman, R., & Gutowski, M. **Planning for independent living rehabilitation: Lessons from the section 130 demonstration.** Washington, DC. The Urban Institute. Undated.

New York State Office of Vocational Rehabilitation. Albany, NY. New York State Education Department. 1979.

Nosek, P., Dart, J., & Dart, Y. **Independent living programs: A management perspective.** Austin, TX: 1981.

Nosek, P., Narita, Y., Dart, Y., & Dart, J. **A philosophical foundation for the independent living and disability rights movement.** ILRU Project. Houston, TX. The Institute of Rehabilitation and Research. 1982.

Reagles, K., Wright, G., & Butler, A. **Correlates of client satisfaction in an expanded vocational rehabilitation program.** Monograph XII. Series 2. Madison, WI. Rehabilitation Research Institute, University of Wisconsin. 1970.

Rehabilitation Brief. **Independent living rehabilitation: Results of five demonstration projects.** Gainesville, FL. Rehabilitation Research Institute, University of Florida. 1979. 29104.

Rigdon, L. **Civil rights of the handicapped.** Washington, DC. White House Conference on Handicapped Individuals, 1977, 59-64.

Roberts, E. Foreword. In S. Stoddard-Pfleuger (Ed.), **Emerging issues in rehabilitation.** Washington, DC. Institute for Research Utilization, 1977.

Roessler, R. **An independent living need survey.** Unpublished document. Fayetteville, AR. Arkansas Rehabilitation Research and Training Center, University of Arkansas. 1980(a).

Roessler, R. Factors affecting client achievement of rehabilitation goals. **Journal of Applied Rehabilitation Counseling,** 1980(b). **11**(4), 169-173.

Roessler, R. **The role of the independent living counselor.** Fayetteville, AR. Arkansas Rehabilitation Research and Training Center, University of Arkansas. 1982.

Roessler, R., & Mack G. **Jonesboro Service Coordination Project Quarterly Report** (March, 1975). Fayetteville, AR. Arkansas Reha-

bilitation Research and Training Center, 1975.

Rubin, S. & Roessler, R. **Foundations of the vocational rehabilitation process.** Baltimore, MD: University Park Press, 1983.

Sands, H., & Kraus, C. Personal adjustment counseling for persons with epilepsy. In G. Wright (Ed), **Epilepsy rehabilitation.** Boston, MA: Little, Brown and Company, 1975, 104-121.

Scheirer, M. Program participants' positive perceptions. Psychological conflict of interest in social program evaluation. **Evaluation Quarterly,** 1978, **2**(1), 53-70.

Schwab, L. **Independent living assessment for persons with disabilities.** Department Report #4. Lincoln, NE. University of Nebraska, Department of Human Development and Family, 1981.

Sigelman, C., Vengroff, L., & Spanhel, C. Disabilities and the concept of life function. **Rehabilitation Counseling Bulletin,** 1979, **23**(2), 103-113.

Stoddard, S. **Evaluation report on the state's independent living centers** (Funded by AB204). Berkeley, CA. Berkeley Planning Associates, 1980.

Stoddard, S. Independent living. In E. Pan, T. Backer, & C. Vash (Eds.), **Annual Review of Rehabilitation (1980).** New York, NY: Springer Publishing Company, 1980, 231-278.

Texas Institute of Rehabilitation and Research. **Registry of independent living programs.** Houston, TX. Independent Living Research Utilization Project, 1982.

The role of vocational rehabilitation in independent living. Fifth Institute on Rehabilitation Issues. Arkansas Rehabilitation Research and Training Center, Arkansas Rehabilitation Services, 1978.

Turem, J., & Nau, L. Comprehensive needs study, Part II. **American Rehabilitation,** 1976, **1**(4), 6-9.

Walls, R., Zane, T., & Thvedt, J. **The independent living behavior checklist.** Morgantown, WV. West Virginia Rehabilitation Research and Training Center, University of West Virginia, 1979.

Wright, S. **Home modification for spinal cord injured people: A New Zealand overview.** Washington, DC. World Rehabilitation Fund, October, 1979.

Zane, T. **The geriatric amputee.** Washington, DC. National Academy of Scienfitic Publishers, 1961.

Appendix

Training Resources and Background Material

The following resources have been identified to serve as background reading material or training supplements. Since some of the materials have sections applicable to several chapters in the manual, the materials are listed by titles with references to the appropriate chapters.

Resource	Chapter
1. Savant, M. ***It's a new day.*** Manhattan Beach, CA: South Bay Mayor's Committee for Employment of Handicapped. Date unknown. Excellent 9 minute film highlighting people who are disabled working and using a variety of assistive devices. Accompanied by a discussion guide.	1
2. Bowe, F. ***Handicapping America: Barriers to disabled people.*** New York: Harper & Row, 1978. A very useful and highly readable review of the barriers faced by people with disabilities in American society. Addresses barriers in employment, education, civil liberties and other areas.	2
3. Bowe, F. ***Rehabilitating America: Toward independence for disabled and elderly people.*** New York: Harper & Row, 1980. A companion book to ***Handicapping America*** providing information on barrier removal and the variety of programs designed to enhance the participation of persons with disabilities in American society.	3
4. DeJong, G. ***The movement for independent living: Origins, ideology, and implications for disability research.*** Boston, MA: Medical Rehabilitation Institute and Tufts-New England Medical Center, 1978. A monograph reviewing independent living as a social movement, the movement's influence on disability services, and the implications of independent living for research in the field.	2
5. Pan, E.L., Backer, T.E., & Vash, C.L. (Eds.). ***Annual review of rehabilitation*** (Vols. 1 & 2). New York: Springer, 1980 & 1981.	

State-of-the-art reviews of a number of important topics in the field of rehabilitation. Significant chapters from each volume for independent living:

Volume 1	
• Rehabilitation Engineering	5
• New Directions in Rehabilitation Outcome	8
• Independent Living	1, 2, 3, 4, 5, 8
• Consumer Involvement in Rehabilitation	2, 4, 5
Volume 2	
• Follow-up Studies in Vocational Rehabilitation	8
• Sexuality and Disability: The Need for Services	5
• The Case Management Model of Human Service Delivery	7
• Organizing and Delivering Rehabilitation Information	5

6. Frieden, L., Richards, L., Cole, J. & Bailey, D. ***ILRU source book: A technical assistance manual on independent living.*** Houston, TX: Texas Institute for Rehabilitation and Research, 1979. — 1, 2, 3, 4, 5

   A very useful compendium of reference materials on legislation, history of the independent living movement, consumer involvement, program funding and related independent living topics.

7. Seventh Institute on Rehabilitation Issues. ***Implementation of independent living programs in rehabilitation.*** Fayetteville, AR: Arkansas Rehabilitation Research and Training Center, 1980. — 1, 2, 3, 4, 5, 6, 8

   A report prepared by a national study group representing vocational rehabilitation and independent living programs with reviews of models, services, staffing, funding, program evaluation and staff training. Provides a thorough yet concise presentation of many important issues in independent living.

8. Fifth Institute on Rehabilitation Issues. ***The role of vocational rehabilitation in independent living.*** Fayetteville, AR: Arkansas Rehabilitation Research and Training Center, 1978. — 2, 5, 6, 7, 8, 9

   A guide to independent living issues and problems

related to integrating vocational rehabilitation and independent living programs.

9. Eighth Institute on Rehabilitation Issues. ***Peer counseling as a rehabilitation resource.*** Fayetteville, AR: Arkansas Rehabilitation Research and Training Center. 1981. 5

   A training guide on the development and use of peer counselors with information on peer counseling models, functions of peer counselors and considerations for implementing peer counseling programs.

10. Cole, J.A., Sperry, J.C., Board, M.A., & Frieden, L. ***New options training manual.*** Houston, TX: The Institute for Rehabilitation and Research. 1979. 4, 5

    A curriculum for providing independent living services in a transitional living model. Provides excellent materials for the conduct of a program. A companion publication by the same authors ***(New Options)*** is available providing an overall review of the program.

11. Independent Living Research Utilization Project. ***Independent living for the handicapped: Anthology.*** Houston, TX: Institute for Rehabilitation and Research, date unknown. 4, 5

    A videotape illustrating six models of independent living programs with brief overviews of each program. Provides some information on program services as well.

12. Katz, A.H. & Martin, K. ***A handbook of services for the handicapped.*** Westport, CT: Greenwood Press. 1982. 5

    A well-documented reference work on common problems and needs of persons with disabilities, and resources available to meet the needs and problems. Includes chapters on physical care, housing, financial assistance, employment, counseling, children's services and recreation and social activities. Also has appendices on advocacy, consumer and voluntary organizations as well as information and referral resources.

13. Magrab, P.R. & Elder, J.O., (Eds.). ***Planning for services to handicapped persons: Community, education, health.*** Baltimore, MD: Paul H. Brookes, 1979. 2, 4, 5

A guide for planners and program development specialists with chapters on topics such as rehabilitation planning, advocacy and the coordination of service delivery systems.

14. DeJong, G. & Hughes, J. ***Report of the Sturbridge Conference on independent living services.*** Boston, MA: Medical Rehabilitation Research and Training Center and Tufts-New England Medical Center, 1980. 10

A very good reference for review of the issues in independent living from the perspective of vocational rehabilitation and independent living program personnel. Addresses issues in service provision, administration, funding, evaluation and accountability, consumer involvement and community participation and attendant care.